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ABSTRACT

The paper discusses counseling approaches with parents of young deaf children with particular emphasis on issues of the deaf community and deaf identity. The cultural implications of deafness are examined, and the effects of their child's deafness on parents' security, status, and aspirations are noted. Examples from counseling groups in urban parent-infant programs are cited to demonstrate potential reactions to considering their child's future and the understanding that frequently develops among parents from very different backgrounds. Issues of racial and ethnic heritage are considered along with issues of status and aspirations. The value of counseling groups for parents is emphasized, and various approaches (including hiring classroom staff who are hearing impaired) to bridging the gap between the hearing and deaf worlds are described. (CL)

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Counseling Hearing Parents of Deaf Children about Deaf Identity and The Deaf Community

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The diagnosis of deafness in a small child is intensely disturbing to hearing parents. Some of these parents have no previous knowledge of or experience with deaf people. Others have varying degrees of awareness, through acquaintances or from the media. But, whatever their level of awareness at the time of diagnosis, the parents' first task is to learn what deafness will mean for their child.

While there are many different problems which parents face in coming to this understanding, this paper will focus on the issues of deaf identity and the deaf community (which parents often call the deaf world). These issues are especially important at the time when the child is diagnosed and during the first year or two in an educational program. After a general discussion about how the terms deaf community and deaf identity are currently being used, the implications of these concepts for the parents' own self-esteem and social status will be discussed. Examples will be given from counseling groups in a parent-infant program in an urban setting.

The issues of deaf identity and the deaf community or deaf world have been of special interest in recent years to writers about deafness (Becker, 1980, Nash & Nash, 1981, Benderly, 1980, Higgins, 1980, Baker & Battison, 1980). This group of authors views deafness culturally in terms of mutual support, group cohesion and common experiences. They assert that the deaf community should be accepted and respected as a separate cultural group, with its own values and language. This cultural perspective is quite different from earlier medical, educational, and psychological perspectives on deafness. Medically, deafness has been defined as a disability which interferes with the reception of speech. Educationally and psychologically deafness has been defined as a handicap which interferes with learning and with relationships. These traditional perspectives are valid and provide essential information to parents but their understanding of deafness will be incomplete without the cultural perspective as well.

Integrating the cultural perspective with the medical, psychological and educational perspectives is a task which has not yet been accomplished by professionals in the field, but work on it is going on. At Gallaudet College in June, 1982, a group of anthropologists, sociologists, linguists, and psychologists held a conference on the sociology of deafness. Many ideas relating the cultural perspective to the other views were presented. A large number of loosely related terms were used without clear definitions. Some of

these terms are "deaf culture," "deaf heritage," "the deaf way," "the deaf world," "the deaf sub-culture," "deaf ethnicity," "the deaf network," "deaf pride," "deaf consciousness," "the deaf minority," "the deaf community," "deaf identity," "deaf awareness," "deaf power" and "being bi-culturally deaf." These terms are most useful if not taken literally. They are helpful if understood as metaphors which suggest parallels to the experiences of larger racial and ethnic groups.

In the last two decades, these racial and ethnic groups have been experiencing an increased awareness of their own uniqueness, and a sense of renewal in discovering their roots. The interest in deaf culture is a development within this broad historical trend. Like many ethnic groups, the deaf community has a common, special language, ties which transcend geographic barriers and shared traditions and values. Like many racial groups, the deaf community has experienced discrimination resulting in outsider status.

One major difference between the deaf community and other cultural groups is that the deaf culture is not learned at home from family, with the exception of deaf children born to deaf parents who comprise only about 10% of the deaf population. It should also be stated that audiological status is not sufficient for inclusion in the deaf community, as the term is commonly used. Some people who are hard of hearing feel a part of the deaf community while others who are profoundly deaf do not identify themselves with it (Higgins, 1980). Some hearing relatives of deaf persons and some professionals who work with the deaf also identify themselves with the deaf community and may be accepted with associate status or courtesy membership (Baker and Cokely, 1980).

Within the larger cultural context of ethnic consciousness and pride which has been evident in the United States in the 60's and 70's, terms such as "deaf culture" and "deaf pride" imply the following statement: We sense that our experience of difference and oppression is similiar in some ways to that of ethnic and racial groups. We, too, wish to gain support from each other and to feel pride in our unique language and values. Deaf identity is usually understood as the sense of one's own uniqueness as continuous over time, with the inability to hear seen as an intrinsic characteristic of the self. If a hearing impaired person does not feel that his deafness is an

inherent part of his self-concept, he cannot be said to have a deaf identity. Within the group of persons who do affirm their own deaf identity, there are varying degrees to which deafness is seen as a central part of an individual's identity. For some, deafness is second only to gender in defining the self. Becker (1980) found that it superseded other aspects of identity such as age, ethnicity and race in a group of elderly deaf she studied in San Francisco. Younger people, who have not grown up in residential schools, may see their deafness as less important than other personal characteristics. Young children probably think of themselves primarily in terms of family relationships. The youngest do not know they are deaf or different.

Becker states that "identity is a rudder that helps one steer through the cultural universe. It not only provides the individual with a sense of self, but enables him or her to relate that sense of self to the surrounding world. Our interaction with others is continuously affected by our identity. We must therefore be conscious of its social and cultural components." (p.39). In this sense, the concepts of deaf identity and deaf community are closely related. Like other outsider groups, many deaf people are drawn towards others like themselves. "Interaction with other deaf people ... tends to reinforce positive feelings about one's abilities and validates one's worth as an individual". (p.41).

This broad perspective, which defines deafness culturally by means of the concepts of deaf identity and the deaf community, provides a framework for understanding the experience of deafness as it is currently being interpreted. This framework will be applied to analyze the experiences of hearing parents as they struggle to understand what deafness will mean for their children.

Most parents think of their normal children as being extensions of themselves. If they have a well-defined ethnic or racial identity, they expect the child will be a part of their world. If they have been disappointed in what they have been able to achieve, they hope their child will do better. Because the child fulfills so many important needs of the parent, the parent is able to feel empathy for the child in return. When parents discover that they have a deaf child, this natural process is interrupted.

As they react to the shock of the diagnosis of deafness, many parents feel that their child has suddenly become a stranger in the family. They do not know what they can hope for from the deaf child. They do not know if he will be able to carry on the family traditions or understand the family values. If they had hopes for the child achieving more than they had been able to do, his deafness dashes their hopes. These disappointments make it very difficult to feel empathy for the child who no longer seems to have the ability to fulfill the parents' needs. Each family will react according to its own unique situation, but almost all feel that their child's deafness represents a threat to their own security, status, or aspirations.

The awareness of the child as different from the parents and as a stranger in the family occurs in a variety of ways. It may happen first when the deaf child has trouble understanding the significance of holidays and family gatherings. Other parents experience deafness as stigma when they venture out in public with the child wearing a conspicious body hearing aid. A few parents do not think of their child as different until they observe or hear about deaf adults in their area and wonder about their lives. Then questions arise about the child's future and his educational and vocational prospects. Eventually, they will become aware of the deaf community. Sorting out this new information and becoming accustomed to their strongly negative feelings is a difficult task.

Parents in urban areas are fortunate that they do not have to face these tasks alone. Parent-infant programs provide many services to parents such as parent counseling, support groups, educational sessions, and opportunities to ask questions of teachers and audiologists. Parent organizations on the state, local, and national levels are also ready to provide support and activities. These services and programs are most helpful if the helping persons, whether professionals or lay persons, have a broad understanding of deaf identity and the deaf community as these concepts are currently being used.

Professionals may wonder if it might not be more appropriate to focus the parents' attention on the child's current phase of development or on the task at hand. If they do, they will miss the opportunity to explore these

topics in depth with the parents. It does create anxiety for parents to have to wait for the answers to their questions about isolation and the outsider status of the deaf to emerge with experience, rather than receiving immediate reassurance from helping persons. But they can usually tolerate their discomfort with support from professionals and from each other. Since their own feelings of having a secure place in the world are at stake, it is worth taking this task very seriously.

Sometimes parents will bring up these concerns themselves. If they have not done so, it is helpful to open the subject by asking about the aspirations they had had for their expected normal child. They can be encouraged to talk about their family history, their present situation and their values about education and achievement. Whatever their marital status and situation in life, hearing parents must reformulate their own identity as they face this new challenge. If a mother is very young her sense of her own identity in relation to the child's grandparents is still in the process of evolving. If she is older and has had other children, her sense of competence as a parent is undermined by the difficulties of managing a deaf child.

Sometimes mothers and fathers interpret the defect in their child as a personal failure. During a discussion of the hated term, "deaf and dumb", a father said, "I'm the one who is a dummy." These changes in parents' self-esteem often lead to feelings of isolation from whatever community they are a part of. This situation is aggravated if the child's grandparents react with blaming or denial.

Several examples will be given of ways that hearing parents have reacted as they begin to reflect on the meaning of their child's deafness to their own identity, their status, their aspirations and to their feeling of belonging in a local community. These examples are drawn from parent counseling groups in the HI-MAPS Project, a hospital based parent-infant program in Chicago. This program draws families from various social and ethnic groups in the inner city, and from middle class suburbs. A few come from rural areas at some distance. Because of this broad range of socio-economic backgrounds it is to be expected that there will be many different reactions when the parents first learn about the average educational and vocational achievements of deaf people. At one end of the continuum are families where

both men and women are expected to enter the professions. Learning to read well and using correct standard English are important values in these families. They are shocked when they hear of the average reading levels of deaf children. They are then willing to go to great lengths to assure that their own deaf child will be among the exceptional few who are high achievers.

At the other end of the continuum are families with multiple social problems and little education. They have already had experience tolerating low functioning individuals within their kinship network. These parents may expect nothing of the deaf child and may need much persuasion that he is of normal intelligence and can be educated.

Most parents of deaf children in the Chicago program fall somewhere between these two extremes. Fluctuations in the economy are felt especially keenly by young families in this middle group. The impact of the recession and the added burden of a deaf child reverses the trend of upward mobility which had characterized their families of origin. It is a common pattern in the inner city for these families to have come north during World War II. They were able to work steadily, though at low paying jobs. Children were encouraged to finish high school and some aspired to a college education. Social programs such as Head Start, CETA, and the Basic Opportunity Grants gave them advantages their parents didn't have. Some of these young people are now finding that because of the recession, they are not able to achieve according to their parents' aspirations for them. Having a deaf child has further complicated their economic disadvantage. Some of the young mothers are not able to work or attend college because day care for deaf children is non-existent. These young women had previously thought of public aid as a temporary expedient, but now wonder what the future will hold for them.

These kinds of disappointments affect middle class parents as well. As most Americans hope that their children will achieve more than they did, educationally and vocationally, having a deaf child requires a different view of the future. Economic uncertainty intensifies the sense of defeat felt at the erosion of their hopes for the child. It is helpful to parents to have opportunities to articulate these frustrations over an extended period

of time. If not brought into the open, they may result in a festering resentment of the child and apathy about learning to communicate.

Other parents may be economically secure but have experienced outsider status themselves in a social sense. This experience sensitizes them to the outsider status implied by the idea of a deaf identity for their child. For example, a young father had immigrated to the United States and his British parents did not accept his American wife. The young couple had little support from her family or from friends. On their own, they struggled to learn sign language so they could communicate with their child. The father talked about how hard it was for him to use his hands and face expressively because of his British upbringing. He knew his son's future would not be the secure world of privilege he had grown up in. It would not even be the isolated but comfortable world he had created for himself. In talking with an inner-city father in a counseling group, he realized that his son would experience not only isolation but would also face discrimination as racial minorities do. He became aware that this would make him angry and that he would need to fight for his child's rights. The two fathers, each from a very different background, were able to support each other.

Another way in which a family's particular situation influences its view of deaf identity and the deaf community is fear that they will not be able to transmit their special values and heritage to the deaf child. This usually happens in families with a strong ethnic identity. While they may not be able to formulate the question in these terms, the key question is fear that the child's deaf identity will be in conflict with his ethnic identity.

Such a concern was discussed by a Hispanic father in a parent counseling group. He talked about how important it was for him to have another child even though it was not medically advisable for his wife to get pregnant again. He was finally able to say that his deaf son would not be able to carry on the family name. This father had only a vague and confused idea about deaf identity and the deaf community, but he perceived his two year old as an outsider, alien to his world. During the course of the discussion, he revealed the fact that some members of his large extended family were still denying that the boy was deaf. They prayed to saints and hoped for a miracle. Other group members reported the same problem. They were able to

give each other the support that was not forthcoming from family members. Later in the year, the Hispanic child's godfather attended a special information session at the parent-infant program. He asked many searching questions and became convinced of the reality of his godson's deafness. He went home, gathered the family together and explained the matter to them. If several members of a large extended family can learn to sign, they can share their own heritage with the child. He will then have a secure place in the world where he can make himself understood. His deaf identity will not be in conflict with his ethnic identity. This process is facilitated by efforts of professionals to include extended family members in parent-infant programs.

Racial issues frequently come up when parents of very different backgrounds are closely associated in a parent-infant program. For some black parents, having to suddenly become dependent upon white middle class professionals stirs up memories of past injustices. One parent talked about her experiences buying a house in a white neighborhood, being harassed, having to have protection from the law, and still, years later, being shunned by the neighbors. Now the neighborhood children were taunting her deaf child. Seeing the two year old smile unknowingly back at them, she realized how helpless the child would be. She could not imagine that her child would be able to stand up to oppression as she had been able to do.

Several examples have been given of ways hearing parents react as they reflect on the meaning of their child's deafness to their own status and aspirations. Some parents were experiencing downward mobility, others had racial issues. One parent was sensitized to the isolation implied by a deaf identity because of his own social isolation. Another parent had a firm ethnic identity but wondered if his deaf child could be a part of his group.

One of the best ways parents can work through these issues is to participate in a counseling group composed of people who are very different from each other. When parents of different social classes, varying educational backgrounds, different races and with a wide age range from teenage to middle-age meet together, these groups are more effective. They will have one thing in common: their children's deafness is threatening their place in the world. By being with each other, they get in touch with their

common humanity. In sharing their pain, they break out of their isolation. The effort involved in trying to understand the problems of parents who are very different from themselves is good practice for thinking about how the deaf child will be different. The honesty that prevails in these groups is a welcome antidote to experiences parents often have with relatives who refuse to accept the reality of the deafness and refuse to learn to communicate with the child. The sense of community parents experience in counseling groups and in parents' organizations lessens their pain. They can gradually come to realize the isolation their deaf children will face because this support gives them courage to be realistic. Their empathy for the child will prepare them to accept his need to be a part of a community himself.

Counseling groups also give parents an opportunity to talk about deaf adults they have met. These discussions help them understand that there are "many ways of being human and many ways of being a deaf human "(Trybus, 1980). By pooling their experiences, they are less likely to have a limited view of what deafness will mean for their children. Some parents may give up on their child if the first person they meet is a deaf peddler. On the other hand, if they meet an educated professional or successful businessman, they may develop expectations for their child which do not take into account the realities of stigma, difficulties in education and limited job opportunities for the average deaf person. Deaf children who have never met a deaf adult sometimes wonder if deaf children die before they grow up or imagine that all children become hearing when they get older.

Some parent-infant programs feel that parents need special services to help them understand the deaf community. Opportunities are provided for them to interact with deaf adults within the program itself. At the parent-infant program in Vancouver, the director is deaf. Pre-lingually deaf adults who are native signers visit each family on a regular basis (Freeman, R., Carbin, C., and Boese, R., 1981). After a time a different deaf adult is assigned to the family so they encounter a variety of sign language "accents", auditory/oral abilities, life experiences and personal styles. In addition, the instructors for the weekly parent night sign class are deaf adults.

Other programs which are center-based introduce children and parents to deaf adults by hiring classroom staff who are hearing impaired. Erting has described a research project in which variations in pre-school children's language was observed as they reacted to hearing and deaf staff (1980).

A third possibility is for deaf parents of deaf infants to be included in parent-infant programs. With an interpreter present in counseling groups, the deaf and hearing parents are able to share many common concerns about the developmental problems of their children.

Through many different experiences with deaf adults over time, hearing parents realize that there is no fixed identity stamped upon the child by his diagnosis. They see that the child's self-esteem and desire to achieve will be influenced primarily by his relationship with his parents, as is the case with hearing children. After they come to this realization, the next step is to understand that the deaf child may wish to be a part of the deaf world or deaf community when he grows up. At the conference at Gallaudet College which was mentioned earlier, this fear was expressed dramatically when the question was asked, "Who owns the deaf child, the parents or the deaf community?" An answer could not be given. The question of ownership is a provocative metaphor for the dilemma faced with disturbingly ambivalent feelings by many parents. In counseling, the parents are helped to see that being able to "own" oneself is a mark of maturity and mental health. For the child to "own" himself when he grows up should be the goal, rather than "ownership" by parents or community. They can compare this need to their own experiences struggling to become independent from their families of origin. As the ability to be self-sufficient is closely related to the development of self-confidence, they will be able to relate this goal to their hopes that the deaf child will be able to be economically independent when he grows up.

Some writers feel that "a strong deaf identity" is necessary for the development of self-esteem. According to Becker:

> The development of a strong deaf identity is critical to the development of a sense of personal well-being, even though deaf identity incorporates negative self-perceptions. Deaf identity is shaped, not only by these negative self perceptions, however, but by a variety of social factors that engender a positive sense of self. The commonality of shared experience, the frequency of interaction with other deaf people, and successful communication about the meaningful, intimate aspects of everyday life all contribute to

> development of a sense of self-esteem that grows with time (Working Papers, 3, 1982, p. 27).

Ideally, a young person can have a sense of belonging in both his hearing parents' world and in the deaf community. Deaf children are fortunate if they find the experience of "successful communication about the intimate aspects of everyday life" within their families. Some will learn to speak well enough to find it in the hearing world. Others will live relatively isolated lives with a few close friends. Many will choose to participate in the deaf community. Deaf identity can be experienced in all of these ways.

Before parents can feel comfortable with this view of the interrelationship between deaf identity and the deaf community, they need many opportunities to discuss their fear that the child will reject or exclude them if he enters the deaf world. This is less likely to happen if the parents themselves have had some contact with the deaf community.

When hearing parents ask for suggestions about how they can approach the deaf community, professionals need to be knowledgeable about a variety of ways in which this can be done. Recommendations should be tailored to the individual style and interests of the hearing family. A possible first step is to attend a function where hearing parents can participate without the necessity of signing on a one to one basis. Some possibilities are political meetings, theatre performances where interpreters are provided, and signed tours of art and science museums.

Parents will be interested to learn about the variety of smaller communities within the larger deaf community. These include groups who attended residential schools together (Becker, 1980) small social groups of the oral deaf (Benderly, 1980), and deaf social clubs organized along racial lives (Higgins, 1980). Finding a church or temple with interpreted services is one of the most common ways parents in the Chicago program first approach the deaf community. The various experiences parents have as they interact with the deaf community help them to anticipate the child's need for a sense of belonging to a group larger than the family. But not all parents are ready to take these steps during the first few years. Some find other ways to build bridges between the hearing world and the deaf world.

One approach to the problem of the deaf child's isolation is to create a small signing community for the child in his own neighborhood. For example, a mother wanted to be able to work part-time so she gathered a group of 13 and 14 year olds in her neighborhood and taught them enough signs to be babysitters. She helped design a babysitters instruction pamphlet for her parent-infant program. In the store where she worked, several deaf persons discovered she was trying to learn sign language and began to come in regularly to practice with her. Later, she suggested to her ear, nose and throat doctor that his office nurses should learn sign since they served so many deaf and hard-of-hearing persons and he carried out her suggestion. Her latest project is to teach a series of sign classes at the local public library which is especially popular with senior citizens.

This kind of activity is easier to carry out in small towns or rural communities. A young family in such a situation reported that a retired deaf couple was helping them learn sign language. Later their relatives and neighbors became interested in learning to sign so they could make the small deaf child comfortable as he grew up. The parents became the teachers and the class grew to number 50 adults and children.

This kind of community spirit may be impossible to achieve in urban situations where people do not know their neighbors. Many families report that other mothers do not want to be bothered with the extra trouble of communicating with the deaf child and so will not welcome him into their homes. These differences in reactions from local hearing communities are important to note before helping persons begin making suggestions to parents. If there is an implication that such community acceptance will be easy, the parent will feel personally inadequate when she experiences lack of interest or hostility.

The task of creating a small communicating community for the deaf child singlehandedly is possible only for self-confident parents who have leisure time for such activities. Those who are busy or are more reserved have a better chance of success if they band together with other parents and share their confidence. For example, a meek young woman was having difficulty in caring for her deaf child because of frequent headaches. During her year in

the parent-infant program, her own conductive hearing loss was discovered and corrected. She became very close to the other parents in her parent counseling group. She gradually learned to be assertive with the agency where her application for financial assistance to buy a hearing aid was bogged down in red tape. After the children transferred to a regular school program at the age of 3, the parents continued to support each other. When problems with bus service developed, this group of parents went directly to the mayor of Chicago and were successful in getting it reinstated.

Parents experience strength in numbers by working with other parents. This process helps them learn a new role, that of advocate. This new role also helps parents learn another way to understand the deaf community. Since one aspect of the cohesiveness of the deaf community is the experience of discrimination, solidarity is enhanced by struggling together for better services and better laws.

A framework for understanding some of the issues faced by hearing parents of deaf children has been presented. Within this framework, the deaf community is seen as deserving of respect as a separate cultural group with its own values and language. The concept of deaf identity has been analyzed in relation to the need for hearing parents to build bridges between the hearing world and the deaf world for their children. Examples from a hospital based parent-infant program serving a broad range of socio-economic groups were used to illustrate this problem.

It has been concluded that parents are not able to carry out this task unless they first work through the meaning of the deaf child's outsider status for their own identity, social position and aspirations. In order to do this, they need support from other parents and opportunities to discuss their experiences in individual and group counseling over an extended period of time.

By the time the child leaves the parent-infant program and starts full-time school at the age of three, many parents are ready to work on this problem actively. Their personal interests, degree of self-confidence, and amount of leisure time will determine the approach they choose. Some parents will decide to attend events within the deaf community. Others will attempt

to create a small signing community within their own hearing world. The role of advocate in working with the deaf community for better services and better laws is another possibility.

Professionals can help by making suggestions and providing opportunities to discuss these new experiences. Sharing feelings of awkwardness and embarrassment gives parents courage to keep trying. As one mother put it, "The first time I met a deaf person, I was all arms and legs!"

Parents experience a sense of community within the counseling groups and other activities of a parent-infant program. This support helps them understand how their deaf children will also need a sense of commonality and belonging as they grow up, both in the hearing world of their families and in the deaf world, should they choose to enter it.